Building a Children's Health Network: City-wide computer linkages among heterogeneous sites for pediatric primary care.

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For many infants and children in our cities, quality of care and health status outcomes suffer due to poor continuity and coordination among ambulatory care sites. Despite proximity to technologically-advanced secondary and tertiary institutions, primary care services for children are fragmented, multiple-site use is common, and data flow among providers serving the same patients is primitive. Preventive and acute health care is often incomplete or redundant, and aggregate information for public health purposes is insufficient.

This paper focuses on the development of a city-wide computer-based pediatric health care network to improve provider decision-making and follow-through, parent role in their children's care, and community-wide data. A process of building consensus for a regional system is presented, addressing issues of establishing a uniform data base, coordination among heterogeneous institutions, system development, confidentiality, and integration with public health reporting and planning functions.

I. INTRODUCTION

In many urban areas infants and children are served by several medical institutions having advanced technical resources. Yet even with access to such facilities, rates of preventable morbidity and mortality remain high, particularly among impoverished, multi-cultural, and mobile populations; and quality of care is often poor, particularly in continuity and coordination, two critical information-dependent features listed by the Institute of Medicine (IOM) and scholars in primary care pediatrics [1]. In such settings in which fragmentation of services and multiple-site use are common, well organized medical records are often unavailable, thereby impairing the efficiency and success of clinical interventions and prevention efforts for children who visit community health centers, hospital emergency departments, and school-based clinics.

While increased access to children's services has been widely addressed, their quality and equality has received less attention. In a national survey, poor children were more likely than non-poor (15% vs 8%) to lack a regular source of ambulatory care (RSAC); and those with a regular source made 80% timely visits for routine care, versus only 48% for those without one. Furthermore, poor children more often (17% vs 6%) receive sick care at a site different from routine care, a discontinuity particularly for those who have access to a community clinic rather than a physician's office (40% vs 4%) [2].

The establishment of a computer-based system to share uniform information among institutions serving these families fulfills several patient record functions in clinical practice, as envisioned in IOM's recent volume [3]: storing data, guiding clinical problem solving, and supporting decision analysis, reminders and risk assessment. The presence of a uniform data base will permit longitudinal follow-up by clinicians and production of hand-held parent records in paper or magnetic copy for personal reference and presentation in new settings.

Such a system will also enhance the public health functions of community needs assessments and planning for efficient resource allocation among projects and agencies. A modern computerized city-wide system assuring individual confidentiality will permit small-area and aggregate data analysis and facilitate new wide-scale treatment outcome studies.

This paper presents the process undertaken to develop a computer-based health care records system for the pediatric community in greater Hartford, Connecticut and other cities.

II. PROCESS OF BUILDING A CITY-WIDE INFORMATION NETWORK AMONG URBAN PRIMARY CARE SITES

During the past year a Children's Health Network was formed in Hartford, supported by the Maternal and Child Health Bureau (Public Health Service). Three years earlier, a concept paper had been written and discussion begun by individuals from the city's three community health centers, three hospital outpatient departments (OPDs), and school-based health services. Initial submissions to two large foundations and requests for corporation hardware donations were unsuccessful. Subsequent work included formation of a multidisciplinary task force

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and data gathering, including a survey assessing multiple-site use of pediatric services. For off-hour visits at a major urban hospital OPD, indication of RSAC was 33% the same institution, 25% another public site, 22% none, and 20% private [4]. Prior records were frequently unavailable even with consistent site use.

Wider discussion and dissemination led to local foundation grants, multi-institutional and state health department support, and then federal funding. Multidisciplinary work groups and a steering committee have been formed to obtain input from community and provider sources, including hospitals, community health centers, school-based clinics, pediatric practices, visiting nurse organizations, technical firms, and city and state agencies. Groups address the following areas:

1. Consensus development and adoption of a uniform database for clinical encounters: we studied and expanded for pediatric use the Uniform Ambulatory Care Data Set proposed by the National Center for Health Statistics.
2. Implementation in the community as Network development proceeds: survey of existing hardware and software resources, compatibility, preferences for data entry method, format of parent-held native-language record, and technical and political obstacles to implementation among heterogeneous sites.
3. Technical features of system design and implementation (elaboration in following sections).
4. Creation of materials and techniques by consultant attorneys to assure security and confidentiality: concordance with individual patient/family preferences and institutional needs; specific informed consent documents and network liability provisions; and compliance with evolving transmission and security standards of federal agencies, professional organizations, and state and federal law.
5. Analysis of aggregate data: procedures for public health reporting and sharing information with outside agencies and researchers.
6. Evaluation: process; data validity and utility; and patient, community, and provider satisfaction.

Many issues remain to be resolved, with space limitations precluding discussion here: details of data base contents, coding methods, and unique identifiers remain tentative, as they should, pending national consensus in this time of intense activity. For current needs of consumers and providers, it appears necessary to proceed with system development and implementation, ensuring flexibility to modify and update upon critical review, comparison with experience elsewhere, and development of techniques and standards at local and national levels.

III. UNIQUE SYSTEM REQUIREMENTS

To support the needs of distributed health care for children as described above there are unique information requirements not present in traditional patient record systems [5]. These unique system requirements are:

- ensure access to patient records from any location,
- ensure that the data is available and on-line with acceptable speed during clinical encounters, at any time of day,
- support communication and information distribution throughout community while retaining security of information, and
- minimize cost of system introduction at each location.

To support these unique requirements we developed an information deployment strategy for heterogeneous systems. This information, to ensure it is current and always available, will be treated as mission critical data. This data criticality then needs to be applied to multiple users and multiple systems across a wide geographical area [6].

IV. ARCHITECTURE STRATEGY

A network supporting multiple users and multiple systems distributed across a wide geographical area requires a complex system architecture. This network architecture needs to be configured to address the needs of the users, overall system capabilities, health care organizations, and various federal and state regulations:

- Access to any child's records from any location,
- Security of access and data,
- Minimize or eliminate inability to access data,
- Interaction using inexpensive computers (e.g., PCs) and phone lines, and
- Ability to access services such as on-line health care databases (e.g., Medline searches).

To support these critical requirements two common architectures were considered: a) the Central Data Repository where the data is contained in one location and terminals access the information, and b) the Wide Area Network (WAN) approach with distributed databases. Both offer advantages as well as disadvantages.

Centrally Based Repository

The centrally based repository architecture involves a single data repository with terminals or computers

accessing data on any child. When the child receives health care at any participating facility the information is accessed from the repository and new data transmitted back to it. Figure 1 shows the Centrally Based Repository architecture.

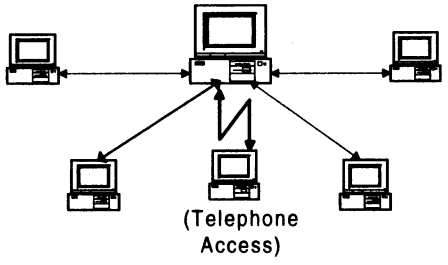

Figure 1. Centrally Based Repository

The advantages realized are:

- Data is in one location allowing consistent access, analysis and back up
- Services can be shared by all users (e.g., database accesses, peripherals)
- Records are available from any connected locations at any time

The disadvantages to this approach are:

- Repository based systems, unless through expensive redundancy efforts, present a single point of failure
- To support real time access from a large group the central computer of repository architectures require extensive and expensive resources, facilities, and equipment

Wide Area Network (WAN) Distributed Client Server Architectures (CSA)

WAN Distributed CSAs support multiple servers maintaining pediatric data for children assigned to a specific location. When a child arrives at a facility other than the one assigned, the appropriate provider computer will be accessed from the "foreign" provider. When health care is provided that server will update the required data back to the child's host server. Figure 2 shows the WAN distributed CSA.

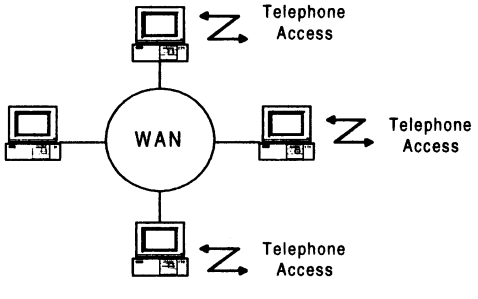

Figure 2. WAN Distributed CSA

Advantages for the Network are:

- Allows local control of data security
- Immediate access to data
- Optimum use of equipment
- Distribution of costs and decreased expenses

Disadvantages to this approach are:

- If server or line is off line, child data is unavailable to "Foreign" provider
- Accessing of remote data needs to be real time

V. DESIGN RECOMMENDATION

Since both architectures provide capabilities required for successful application of a database in support of the Children's Health Network, it was decided to implement a hybrid, hierarchical based Client Server Architecture with a major server providing the role of Central Data Repository. The distributed network will provide the real time, direct access support, with the repository receiving scheduled updates with access when distributed servers are off line. This hybrid architecture is shown in Figure 3.

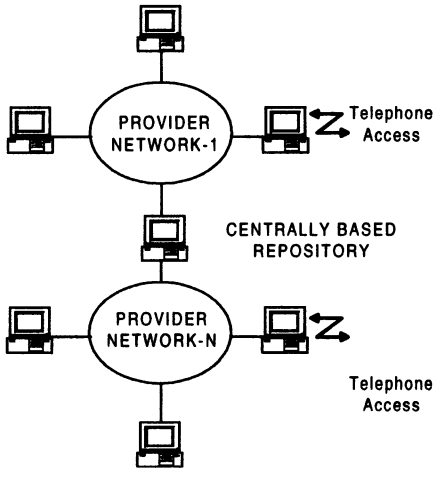

Figure 3. Hybrid Distributed CSA

Implementing a distributed CSA with a server providing the function of a central repository without the real time access (i.e., scheduled updates) provides advantages of both architectures. This approach also resolves data latency and retention needs [7]:

- Data is in one location allowing consistent access, analysis and back up
- Services can be shared by all users (e.g., database accesses, peripherals)
- Records are available from any connected locations at any time
- Allows ownership and control of data
- Immediate access to data

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- Immediate access to data
- Optimum use of equipment
- Distribution of costs and decreased expenses

The disadvantage to this approach is:

- Cost is higher than a distributed CSA

Although it can be costly to implement a server as a central repository, this additional cost can be minimized by carefully selecting large servers as repositories.

To support this capability, the following network characteristics will be implemented:

- All computers will be Intel processor and Windows based
- Repository will retain all transactions and records shared by providers
- Overall architecture will be Client Server Architecture (CSA) and Structural Query Language (SQL) compliant.
- Support will be Integrated Services Digital Network (ISDN), 2400, etc.
- Providers (e.g. clients in CSA) with "foreign" patients, will automatically access identified provider (e.g. server in CSA)
- Upon a transaction, provider will update repository records
- If provider does not answer system, client and/or providers with "foreign" patients, will access the repository
- The provider will access the repository upon start-up and periodically to ensure data integrity

Building Block Approach

The overall goal of the project, if the prototype is successful, is to deploy the network in a broader geographical area. This will be done by applying a hierarchical posture to the repositories as the prototype network is expanded to the city, state, regional, and possibly national levels. Implementing in this method allows the development to proceed leveraging previous efforts including the prototype towards this final goal. This building block approach, will allow the network to expand throughout the city, region, state, and hopefully the country. The distributed CSA will minimize costs and retain ownership and privacy while the repositories provide data and access redundancy, information interchange between health care organizations, and a comprehensive overview (e.g., contagious outbreaks). In addition, the structure of the repositories position the network for easy integration into the National Information Infrastructure (NII) allowing an even broader interchange. This hierarchical based expanded hybrid design is shown in Figure 4.

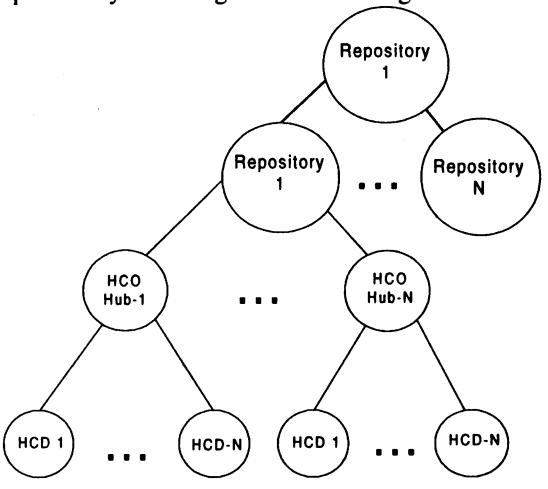

Figure 4. Hierarchical Expanded Design

The regionally (e.g., City, State) defined repositories are characterized as:

- Large organizations - hospitals, research institutes
- Community defined (e.g. City, County)

The Health Care Organizations (HCO) are:

- Hospitals (small/medium)
- Walk-in clinics
- Practitioner's organizations

The Health Care Deliverer (HCD) is characterized as:

- Small doctors offices
- Specialist
- Nurses - school, home care
- Facility or specialty defined (e.g. school)

VI. PROTOTYPE SYSTEM

The primary decision factor in the software to support the prototype system (i.e., one school, one hospital) is the means to retain and update all consented students records, and the ability to enter, track and report information associated with the students. This information includes:

- Students demographics
- Abstracted (coded) medical history and text
- Medical treatment and recommended follow-up.

Essentially the software required to support retaining, maintaining and updating this information is tasked to provide data management services.

As a result of overall implementations throughout the industry, the following system requirements for the school / hospital connection have been identified:

- Operates on a desktop 486 with modem support
- Supports client server architecture
- Operates with windows.

Since the ultimate goal is to interact and coordinate records from multiple sites, the following capabilities of the system need to be considered:

- Distributed processing
- Multiple platform support
- Changing requirements and data structures
- Interaction with "foreign" data bases and systems
- Data integrity and retention

VII. CONCLUSION

Applications of specific databases, such as for immunizations and lead toxicity, have become available, and a variety of comprehensive clinical systems for individual institutions are in place. But automated ambulatory record systems shared among distinct sites are not common; there are numerous obstacles to their design and implementation such as lack of standardization, incompleteness, inaccuracy, and security concerns [8]. Other problems include interface design for heterogeneous databases and political issues of data sharing among a variety of health institutions and agencies [9].

Even within a context of urban poverty and poor health, the technical capability to narrow the gap between reality and potential exists. Lack of systematic and patient-sensitive means to acquire and share data has impaired the consistency, continuity, and coordination needed for quality care and improved health outcomes for infants and children.

Development of this computer-based, client-server, distributed database system is underway. The design approaches mentioned above, (i.e., a transaction-based central database server with network/modem connectivity), will provide remote access while maintaining the integrity and security of the database. Although this system meets the needs of the pediatric community, similar strategies can be employed for developing a more complete patient-based record for the general population.

The implementation phase will enable us to test the data screens designed by our clinical work group and assess the utility of this effort. The key requirement for this system is to satisfy the clinical staff who need and use the information contained in the database. Only if the system is used by the clinical staff will it be successful.

Acknowledgment

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References

[1]. B. Starfield. Primary care: Concept, Evaluation, and Policy. Oxford University, New York, 1992.

[2]. Robert F. St. Peter, Paul W. Newacheck, Neal Halfon. Access to Care for Poor Children: Separate and Unequal? *JAMA* 267:20;2760-2764.

[3]. Richard S. Dick and Elaine B. Steen. The Computer-Based Patient Record. National Academy Press, Washington, D.C. 1991

[4]. Larry Deutsch, unpublished research.

[5]. David Trace, Frank Naeymi-Rad, David Haines, J.J. Shanthi Robert, Fabio DeSouza Almeida, Lowell Carmony, and Martha Evans, Intelligent Medical Record Entry (IMR-E) *Journal of Medical Systems,* Vol. 17, Nos. 314: 139-151 1993

[6]. Henry C. Chueh, M.D., M.S. and G. Octo Barnett, M.D., Client-Server, Distributed Database Strategies in a Healthcare Record Systems for a Homeless Population. Proceedings of 17th annual Symposium on Computer applications in Medical Care. McGraw Hill, Pg 119-124, 1994.

[7]. Bill Rosenblatt, UNIX RDBMS: The next generation, *February 1994, Advanced Systems:* 82-90

[8]. M.L. Grady, H. A. Schwartz. Automated Data Sources For Ambulatory Care Effectiveness Research. AHCPR, USDHHS, 1993.

[9]. K.A. Marrs, S.A. Steib, C.A. Abrams, M.G. Kahn. Unifying Heterogeneous Distributed Clinical Data In A Relational Database. Proceedings of 17th annual Symposium on Computer applications in Medical Care. McGraw Hill, Pg 644-648, 1994.